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ABSTRACT

The second of three manuals on attendant care for disabled persons is intended for parents of severely handicapped youth. An initial message reviews typcial reactions of parents to their child's quest for independence while subsequent sections address the basic principles of independent living and parents' responsibility for structuring learning experiences to promote responsible decision-making. Three independent living support systems are identified: (1) community support, (2) agency support, and (3) personal-emotional support. Guidelines on when to use personal care attendants and a list of resources conclude the manual. (CL)

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A Message to Parents of Handicapped Youth

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PREFACE

As its title suggests, this booklet addresses itself to parents of handicapped youth and adults who are trying to assume greater responsibility and self direction. The content is equally applicable, however, to other relatives, spouses, or any person who has primary responsibility for a handicapped person's physical care.

Part of the material may have more meaning to some people than to others. This is because of the two major classifications of disability: (1) *congenital disabilities* affect individuals at birth and (2) *acquired disabilities*, through injury or disease, can occur at any time in a person's life. The section on **TEACHING RESPONSIBILITY** might be more meaningful to parents of children with congenital disabilities because individuals with acquired disabilities may have already learned responsibility and good decision-making skills from normal maturational development (depending upon the age at the time of onset of the disability).

It is hoped that you will benefit from all of the material presented. The content was drawn from the experiences of many families dealing with a disability as well as handicapped people who are successfully living independently. Much of the work in developing the issues in self-management skills was developed in the New Options Transitional Living Program, The Institute for Rehabilitation and Research (TIRR), Houston, Texas.

INDEPENDENT LIVING WITH ATTENDANT CARE: A Message to Parents of Handicapped Youth

This booklet is one of 3 in a series designed to promote independent living for severely disabled people who require assistance in activities of daily living; the series is also a guide for dealing with complex issues in relationships between handicapped individuals and those persons who assist them in their personal care.

As parents of a disabled child, you have probably been the major care providers. Depending upon the time of onset of the disabling condition, you have provided physical assistance for a short time or perhaps for many years. You might feel that it is your responsibility to take care of your family member for as long as you are able. Or you might feel some guilt or resentment that you are not able to devote as much time to other members of your family who probably need you just as much. Maybe you are ignoring your needs for leisure time or perhaps you simply desire a break from responsibility or demands from your physically dependent family member. All of these feelings are natural; in fact, parents normally experience a range of emotions when dealing with a physical disability in their family. These emotions vary from total devotion to the individual with a handicap to feelings of entrapment or a wish to escape from the burdens of the situation.

Often parents are unable to visualize a different environment outside of their home for their handicapped child. Sometimes parents are so involved with dealing with the present that they do not have the energy to plan for the future of their child. Some parents believe there can be no future for their child outside of the home environment but this belief is usually because the parents do not have enough information or positive examples of other alternatives. Still other parents fear that their handicapped child will be institutionalized if they are not able to care for him/her. A common misconception of parents is that they will outlive their disabled child or that the child will always remain a child. These parents are not prepared when the "child" begins his/her quest for independence, "like 'normal' people."

Do you recognize yourself in any of the examples above? If so, this booklet may help you to examine your relationship with your handicapped child. Additionally, you might discover some new options for yourself and your child as well as your entire family.

INDEPENDENT LIVING

If independent living is a goal for handicapped people it is important that you understand what this means for it is more than simply moving away from home to another environment. Independent living means accepting adult responsibilities, using good judgment in making decisions, looking at all of the available alternatives and choosing appropriately. In short, independent living requires that the handicapped person be able to have control over his own life and to direct his own affairs as much as possible. Using this definition, the physical environment has little to do with independent living although the arrangement of the environment (i.e., the removal of architectural barriers) might increase the level of functional independence for the disabled person. Thus, a handicapped individual can essentially achieve independent living in a variety of settings including his family home, an apartment complex, a dormitory room at a college or university, a house in a residential neighborhood, or even a nursing home. The critical variable is whether or not the disabled person is able to play a major role in deciding what happens to him in his day-to-day activities.

Many handicapped adults have related that independence for them means having choices—being able to choose where they live, where they work, how they get from place to place (transportation), how they spend their spare time, and who provides their personal care. Independence can also be something as simple as being able to choose what to wear everyday. One handicapped woman, away at college for the first time, was surprised when her roommate/attendant asked her what she wanted to wear to class the first day. This woman's mother had always chosen her clothes for her each day. Fortunately, the handicapped woman accepted this new responsibility as a challenge; another choice for her, however, would have been to allow (or to force) someone else to make her decisions for her.

TEACHING RESPONSIBILITY

Thinking about your own growing up years, consider how you learned to make decisions and accept responsibility. Most children are assigned tasks to do around the house such as putting away their toys, taking out the garbage, setting the table, etc. As the child becomes older, more responsible tasks are delegated that require more and more responsible behavior. For example, mowing the lawn requires that the child use good judgment regarding safety practices in using a lawnmower, gasoline, etc. The child might learn through observation at first, then by performing the task with a responsible person, and finally by doing the task alone. Usually, a system of rewards and punishment is also imposed upon the child. Parents will say "If you don't clean up your room, you can't watch TV tonight" or "After you finish your chores, you can go outside to play." Again, the child will test out new behaviors and gain more responsibility with age. When the child is ready to move into adulthood, he has probably had a number of years experience in making decisions for himself; this practice will enable him to use good judgment in weighing alternatives and making good decisions in his adult life.

The process described above is somewhat different for the handicapped child or youth. Attitudes toward disability dictate that the handicapped person should be absolved from all responsibility and should be taken care of and protected. The problem with this attitude is that the handicapped child does grow up to become an adult. The child ordinarily develops hopes and desires for a "normal" lifestyle; although he realizes that he is different through exposure to television, peers, and able-bodied siblings, he often wishes to be just like everyone else. The child needs to learn how to deal with the day-to-day problems and frustrations of life since it is naive to believe that someone else will always be available to protect the child and to make all of his decisions for him. By assuming this overprotective stance, parents can interfere with the child's potential for personal growth, setting life goals, and learning responsibility.

As with their non-disabled children, parents have an obligation to structure learning experiences for the handicapped child. One way to do this is by allowing the child to make decisions for himself rather than the parents making all of his decisions for him. This does not mean that parents shouldn't provide guidelines or limit the choices in certain instances. The point is to allow some choices for the child with a disability. For example, do you arbitrarily choose what your child will wear each day? Some handicapped adults report that they were never encouraged to shop for their own clothes as children or youth. Consequently, as adults they had difficulty defining their own tastes in clothes; choosing from the myriad of styles available became a chore rather than a pleasure.

Another way to teach responsibility is through participation in daily activities. For example, the handicapped child can be included in meal preparation by being assigned tasks such as tearing lettuce for a salad, stirring the eggs, telling the parent when the soup begins to boil, keeping the time on baked goods, etc. Another important activity is being able to deal with merchants in the community and to handle money. Whenever possible, handicapped children should accompany parents to the grocery store, clothing and hardware stores, restaurants, and banks. At first, the child will learn by observing. Eventually, however, he should be given responsibility for making simple transactions on his own (for example, purchasing and paying for a soft drink). If a handicapped child is unable physically to handle his money he should learn how to ask a salesperson or cashier to help him make his transaction. These practical experiences will help prepare the child for later responsibilities as an adult, i.e. the child will already be familiar with normal adult procedures in routine activities.

INDEPENDENT LIVING SUPPORT SYSTEMS

Everyone depends upon different support systems to enhance and to help maintain their individual lifestyles. These support systems may include emotional support such as friends, family, clubs, and churches as well as concrete service provider support systems such as public transportation, social service agencies, and public utilities. Many of these support systems are probably taken for granted (e.g. city water services) while others require a substantial expenditure of personal energy (e.g. public transportation systems).

Disabled people depend on these same support systems but they also rely upon specialized support systems such as attendant care or modified vehicles for transportation. Basically, support systems for independent living can be sorted into three main categories: *Community Support, Agency Support, and Personal—Emotional Support.*

1) *Community Support*

In order for a severely disabled person to live successfully in the community there must be a variety of conditions met by the community. Adequate housing must be available; that is, housing must be architecturally accessible as well as be located near sources of transportation and work sites. Attendant care is another community support system that is a necessity for most severely handicapped people. The importance of this system is being recognized across the country, and independent living programs are paying more attention to training personal care attendants and the handicapped people who will use their services. Some cities have established referral and information services to match up disabled people and prospective attendants. Transportation is another important element in independent living. Although some handicapped people are able to drive their own specially modified vans or cars, many must rely on public transportation systems to take them from place to place. Some cities provide special bus services, dial-a-ride systems, or vans with modifications used as cabs. Maintenance systems must also be available to disabled people living in the community. These include shops and servicemen to repair wheelchairs, home equipment or devices, and van or automobile modifications such as lifts and hand controls.

2) *Agency Support*

Because of the extra expenses related to having a disability, many disabled people depend upon several agencies for supplements to their income. For example, in Texas the Department of Human Resources will help pay for attendant care to those handicapped people who meet their eligibility requirements. The state Department of Vocational Rehabilitation can usually pay for support services to disabled people who are attending school or who are participating in other job-related training. The local Housing and Urban Development (HUD) office can arrange rent subsidy to disabled people living in eligible housing facilities. And, of course, most disabled people are aware of the two Social Security programs, Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). Besides financial support, some agencies also offer direct services to their clients. For example, vocational rehabilitation counselors not only assist a person in determining a

vocational future but can also provide personal adjustment counseling, information about products and services, and referral to other support systems. Most rehabilitation facilities offer similar services although not on a drop-in basis. It is helpful for the handicapped individual to be aware of the network of agency support systems that are available to him so that if one system fails to meet his needs, there are other options available.

3) *Personal—Emotional Support*

Everyone has a need for personal and emotional support through family, friends and/or spouses. This is an especially important variable for the disabled person who might be hesitant to take the risk of trying to live independently. One handicapped individual reported that he couldn't have moved away from his family without their support. In other words, he was able to take the risk knowing that if he needed help, he had his family to fall back on. Friends also play an important role in providing personal and emotional support. No one wants to live in a vacuum, and accessibility to friends and leisure activities is equally as important as architectural accessibility.

SELF-DIRECTION

As you can see, there are many variables that relate to successful independent living. Although the support systems described above are important, probably the most critical issues are the handicapped person's ability to locate resources, evaluate his own life situation, solve problems, make good decisions and in general, direct his own affairs. It is possible for the disabled person to engage in these activities even if he/she is living at home with the immediate family. For example, some families hire personal care attendants to come into the home to assist with the physical care of the disabled family member. In this situation, the handicapped person can be given sole responsibility for interviewing and hiring the attendant; he should also direct his own care by directly providing instructions and describing his own daily routines. This is often very difficult for the person who has had his care done to or for him by his family. Some handicapped people are not even aware of their own care routines because someone else has always assumed that responsibility for them. To be sure, totally relying on someone else is easier but it does not promote self-reliance in the absence of the primary provider. Neither does it allow the handicapped person to practice giving instructions or negotiating compromises with a personal care attendant, both of which are important skills for successful independent living.

By allowing and encouraging your handicapped child or youth to actively participate in all aspects of daily life, you are helping him/her grow. The disabled person will then be able to enter the mainstream with the skills, attitudes, and fortitude to accomplish any goals. More and more choices will be available as the handicapped person acquires self-confidence through using the skills described. Independent living can be a reality with your help and support.

WHEN TO USE PERSONAL CARE ATTENDANTS (PCA)

Many severely disabled young adults are able to live independently with the assistance of a PCA. Personal care attendants are people hired by the disabled person to assist with activities of daily living. The issues of how to locate, hire, and interview prospective PCA's are discussed in another booklet in the series, **Independent Living With Attendant Care: A Guide for the Person With a Disability.** This booklet also deals with communication skills and the relationship between the disabled person and the PCA. Although the assumption is that the handicapped individual will use a PCA outside of his immediate family's home, there are numerous other situations where a PCA could be helpful.

Families might decide to use PCA's on a part-time basis (1) *to relieve them of some of the physical care activities,* (2) *to give them more leisure time,* or (3) *to provide self-direction practice for the disabled person.* When both parents work, a PCA can assist with the often harried morning and evening peak hours when dressing and grooming activities are priorities. Sometimes PCA's can help lessen embarrassment on the part of a disabled adolescent male who is reluctant to have his mother or other female perform personal care. Using PCA's at appropriate times can also prevent an overly dependent relationship between the handicapped child and the parent who provides most of his/her care. Not only is it natural for the child to cling to the security of the major care provider, there is also a danger that the parent will depend upon the child to fulfill the parent's needs for purpose and usefulness.

Sometimes handicapped adults choose to live in the same household with their parents or immediate family. These disabled adults might use PCA's to define their own adulthood. That is, by using PCA assistance, they acknowledge that they are able to take care of themselves in an adult manner with adult responsibilities rather than maintain a "child"/parent relationship within the home environment. One respirator-dependent handicapped man living with his parents works full-time and pays his parents room and board. He relies on attendant care for dressing and grooming activities. He feels that it is economically more feasible as well as more secure to remain at home with his family.

In a marriage situation when one spouse is disabled, the couple might decide to use a PCA to physically enhance and/or restore the equal partnership implied in a marriage relationship. In many marriages, the non-disabled partner might feel that he/she is carrying an unfair share of the burden. Resentments can build and conflict results. The roles in such marriages can be better balanced when a PCA is used to enable the disabled partner to assume responsibility for his/her own personal care activities.

SUMMARY

This booklet has raised a number of issues regarding Independent Living and handicapped youth and adults.

1) **Handicapped children and youth** need to develop certain adult skills that will enable them to assume responsibility for their own lives.

2) **Parents of handicapped youth** and adults have a responsibility to provide learning experiences that will help their disabled children develop responsible behavior.

3) **Parents of handicapped youth and adults** need to be aware of the range of resources and options available which encourage Independent Living opportunities.

4) **Personal care attendants** can be employed in a variety of settings to foster Independent Living skills. The appropriate use of PCA's can potentially improve family and inter-personal relationships.

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This is one of three booklets in a series about Independent Living and Attendant Care. The titles in the series are:

Independent Living With Attendant Care: A Guide for the Person With A Disability

Independent Living With Attendant Care: A Message to Parents of Handicapped Youth

Independent Living With Attendant Care: A Guide for the Personal Care Attendant

The content of each booklet is a result of three years experience in the New Options Transitional Living Program at The Institute for Rehabilitation and Research (TIRR), Houston, Texas. The material was gathered from New Options participants, staff associates, attendants, and families who shared their personal experiences. Each booklet is intended to be a guide with suggestions that can be adapted to each individual's situation.

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Mary Ann Board has a background in Social Work and was the Personal Independence Counselor in the New Options program.

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